

# Advances in Defining, Conceptualizing, and Measuring Quality of Life in Pediatric Patients With Cancer

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**Purpose/Objectives:** To describe the notable advances in defining, conceptualizing, and measuring quality of life (QOL) in pediatric patients with cancer since the 1995 Oncology Nursing Society's State-of-the-Knowledge Conference on QOL.

**Data Sources:** Published research, clinical papers, and hospital policies.

**Data Synthesis:** QOL ratings from children and adolescents are being solicited increasingly in research and clinical assessments during treatment and survivorship using various methods but are not solicited from terminally ill patients; qualitatively induced models of pediatric cancer-related QOL now are being tested using quantitative methods.

**Conclusions:** Children aged five years and older are able to report their cancer-related QOL; reliable and valid QOL instruments exist for all phases of treatment except end of life.

**Implications for Nursing:** Nurses can involve children and adolescents in rating their QOL for research and clinical purposes and can apply theory-based QOL models to direct care.

Knowing what comprises quality of life (QOL) for children and adolescents during cancer treatment, how to measure their QOL, and how to translate the findings into terms that benefit patient care could have significant implications for cancer clinical care, research, and policy development. Accurate, sensitive, and well-timed QOL measurements could be the determining factor in clinical situations when two treatments have similar survival outcomes but differing demands on the other aspects of patients' lives. Being able to clinically evaluate the QOL of children and adolescents will help to more completely assess the full immediate and later effects of existing or future anticancer therapies and other therapeutic interventions. Accurate, longitudinal clinical assessments of pediatric cancer-related QOL will identify the points in treatment that are most demanding, thus providing the design framework for intervention studies intended to prevent or reduce treatment demands on patients and their family members. A combined clinical and research approach to pediatric cancer-related QOL could help to identify the indicators of quality care for children and adolescents from the point of diagnosis to survivorship or the end of life. The purpose of this article is to describe the notable advances in defining, conceptualizing, and measuring QOL in pediatric patients with cancer since the Oncology Nursing Society's State-of-the-Knowledge Conference on QOL convened in

## Key Points . . .

- Significant advances have occurred since the mid-1990s in defining, conceptualizing, and measuring pediatric cancer-related quality of life (QOL).
- Measuring a child's or an adolescent's cancer-related QOL has taken place at all points of treatment, including survivorship, but not at the end of life.
- Nurses can involve patients, parents, and staff proxies in estimating pediatric patients' cancer-related QOL and can use the ratings to guide care.

1995 with support from Amgen, Inc., USA and Amgen, Inc., Canada (King et al., 1997). Application of these advances to the care of pediatric patients with cancer also is addressed.

## Advances in Defining Quality of Life

One of the advances in pediatric cancer-related QOL has been in defining this construct from the perspective of children or adolescents diagnosed with and receiving treatment for cancer. Previously, relevant research reports did not include a definition of pediatric QOL (Bradlyn, Harris, Warner, Ritchey, & Zaboy, 1993; Czyzewski, Mariotto, Bartholomew, LeCompte, & Sockrider, 1994) or, instead, provided a description that was derived from adult QOL perspectives or clinical observations (Barr et al., 2000; Seid, Varni, Rode, & Katz, 1999). More specifically, a definition of QOL as reported by the children or adolescents being treated for cancer had not been

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